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AUTHOR	Ziegler, Martha
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ABSTRACT

This issue of the "Early Childhood Bulletin" is a summary of information that was presented at a 1996 conference on autism sponsored by the National Early Childhood Technical Assistance System (NECTAS). Participants included Part H and Part B, Section 619 Program coordinators, individual program providers, and Interagency Coordinating Council (ICC) parents of children with autism. The single overriding theme discussed was the need for family support in a variety of forms, including parent training, in-school respite care, and programs for keeping children occupied during school vacations. Parents at the conference all agreed that one of the hardest challenges they face is choosing which method of intervention to try. Evidence was cited that supports a multiple approach to intervention and education. Another issue discussed was the great variation among individual children within the overall category of autism. One critical need that emerged from the conference was the need for more research, especially in the area of outcomes and efficacy. Two books on autism are briefly reviewed at the end of the bulletin: "Thinking in Pictures and Other Reports from My Life" (Temple Grandin) and "Out of Silence" (Russell Martin). (SG)

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COALITION QUARTERLY

EARLY CHILDHOOD BULLETIN

REPORT ON AUTISM CONFERENCE SPONSORED BY NEC*TAS

WINTER

1996

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Coalition Quarterly

EARLY CHILDHOOD BULLETIN

News by and for Parents and Parent Members of State Interagency Coordinating Councils

Winter

Prepared by the Federation for Children with Special Needs
Parent Component Staff of NEC*TAS

1996

REPORT ON AUTISM CONFERENCE
*Sponsored by NEC*TAS*

This issue of **Early Childhood Bulletin** *is a summary update on programs for young children with autism. The article has been written by Martha Ziegler, parent of an adult daughter with autism and project director of the parent component of NEC*TAS (National Early Childhood Technical Assistance System), located at the Federation for Children with Special Needs in Boston. While some of the comments here stem from Ziegler's years of experience as a parent and advocate, most of the information was presented at a conference on autism for interested Part H and Section 619 state program coordinators and Interagency Coordinating Council (ICC) parents of children with autism. The conference was held in Hartford, Connecticut, in February 1996.*

It is gratifying to find so much interest in autism among Part H and Section 619 Program Coordinators. This recent surge of interest bodes well both for parents and for young children with autism. It seems to indicate that children are being identified at an earlier age than had been occurring and in addition, more are being referred for early intervention and preschool programs.

Also encouraging is the fact that the federal programs for early childhood special education may well offer the solution that has been so badly needed in the field of autism for many years: namely, the integration of fragmentary and isolated approaches to the education of children with autism.

A major reason for the nationwide interest in autism by early childhood educators is the current (or recurrent?) controversy around some of the interventions being recommended, especially 'discrete trial' methodology, or the Lovaas approach as it is sometimes referred to. Over the last 25 or 30 years, autism has been plagued with one 'magic cure' after another. Often each new therapy offers some actual help but never the cure that has been promised.

A recent conference sponsored by NEC*TAS brought together Part H and Section 619 Program coordinators, individual program providers, and Interagency Coordinating Council (ICC) parents of children with autism. The single overriding theme that emerged from the proceedings was the importance of family support, in a variety of forms. In the opening panel, parents spoke about this need; they all talked about the impact of the disability on the whole family and about the need for support and assistance. One parent said 'Who most needed help was ME!' A father said that he and his wife had needed a 'family advocate,' and they benefited greatly from opportunities to network with other families. A third panelist, who is both a parent and a professional, talked about the importance of training in the home. A fourth panelist discussed the importance of effective communication with the professionals who are working with her son and the importance of her own validation by these professionals.

Several program providers began their presentations by saying that their highest priority also is family support. That term varied some in precise meaning, but the universal awareness of need was impressive. Forms of support ranged from parent training to in-school respite care, a program for keeping children occupied during school vacations.

Parents at the conference all agreed that one of the

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hardest challenges they face is choosing which method of intervention to try. Dr. Susan Izeman, from the Pennsylvania Department of Education, presented the following 'Points to Ponder,' a list of questions to be considered by both parents and providers in assessing the various options for intervention:

1. **What are the anticipated outcomes of this intervention?**
   What positive changes can I expect to see in my child's behavior, communication, eating, sleeping, learning, etc.?
   Do these outcomes address what I see as an area of need for my child?
   Do these outcomes match my expectations or goals for my child?
   Are there any potentially negative outcomes of the intervention?
2. **How will this be evaluated?**
   How will I know if my child is making progress toward desired outcomes?
   What method will be used to evaluate child progress?
   How often will we evaluate child progress?
   Who will conduct the evaluation?
   How long will we continue until a change can be made in the intervention?
3. **What are the potential risks?**
   Will my child face any immediate risk?
   Are there any risks for other family members?
   Are there any activities, foods, etc. that will be restricted?
4. **What is the back-up plan if we choose to discontinue this intervention?**
   Is there any risk of discontinuing the intervention?
   What kind of early intervention services will my child receive if we decide to stop the intervention?
5. **Is there a good fit between the intervention and our family life?**
   Can we do what will be asked of us?
6. **Have I gotten information about this from a variety of sources?**
7. **Is this intervention published in peer-reviewed journals?**
8. **Are there alternatives that are:**
   less restrictive?
   better researched?
9. **How will this new intervention be combined with strategies and therapies that we are already using with my child?**

(Dr. Izeman has acknowledged contributions to her work from Dr. Phillip Strain, University of Colorado; Lori Mousetis, Coordinator of Speech Services, Project DART, Allegheny Intermediate Unit, Pittsburgh; and the staff of the LEAP Preschool, an integrated preschool associated with the D. T. Watson School, Pittsburgh.)

Parents may want to add other questions to this list. Dr. Izeman has suggested that a "Yes" or "No" to any one question should not mean an automatic acceptance or rejection of a particular method. Rather, she suggests that the questions be taken as a whole, as a guide to seeking information.

Another theme that permeated the meeting was the great variation among individual children within the overall category of autism. This theme began with the discussion of labels: autism, PDD (pervasive developmental disorder), Asperger's Syndrome, and others. Most experts seem to agree that all these terms are really aspects of autism and that they simply confirm the importance of recognizing the individuality of children with autism.

Mark Greenstein, a pediatrician and geneticist from Connecticut, talked about the three fundamental domains of dysfunction that characterize autism and the varying degrees of severity that can occur in any of the three: social behaviors, communication (verbal and nonverbal), and interests and attention. Greenstein, along with several other speakers, emphasized the fact that all behavior in autistic children is communicative. Greenstein and others have explained that children and adults with autism become more and more frustrated and anxious when either (1) they are misunderstood or (2) they misunderstand others, and that the frustration and anxiety often get acted out with what appears to be random aggressive behavior.

Greenstein explained some of the strange habits of autistic children by observing that their linguistic concept of time is gone, that they live in a "perpetual present." Change of many kinds produces consuming fear for them, for they have great problems with adaptation. (During my daughter's early childhood years she would be obsessive about toys, while never playing with them in a developmentally appropriate way. When the gingerbread boy would begin to wear out, I would rush to the store to buy a new one, hoping that she would not notice the difference. If the gingerbread boy was not immediately available, in the washing machine for instance, she would cry inconsolably. Panic set in

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when the stores suddenly stopped carrying the gingerbread boy and desperate, I went to a fabric store, bought similar material, and made "new skin" for him.)

Greenstein reported that the incidence of autism has increased markedly on the East Coast during the last seven years and that it is starting to rise on the West Coast as well; he anticipates that the Midwest will eventually follow. He said that the incidence of autism is now the same as Down syndrome: 1.5 per 1,000. No one is certain about the reason for this increase; it may be a result of improved diagnosis, it may be caused by something new in the environment, or it may have some other cause.

During informal networking, parents compared notes about a variety of techniques, especially the use of prescription drugs for their children. They described positive experiences from Prozac, Zoloft, Depakote, and others, often in combination with other drugs. At this conference, as at other conferences, parents indicated that the best results occurred when their children received several different kinds of intervention, such as medication, sensory integration, behavior modification, speech and language therapy, and at least some inclusion with nondisabled peers.

The latest literature on autism, including the books listed below, contains evidence that supports this multiple approach to education and intervention. There can be no doubt that the child with autism has difficulty processing sensory information, and that difficulty may take differing forms. Sometimes the problem and the solution can be amazingly simple: For example, recently my daughter, who lives and works semi-independently, became totally confused about a new job that she expected to undertake. After she walked to the wrong bakery on the wrong day, I finally realized that she had misunderstood what her job coach had told her, almost certainly because the job coach had talked too fast! Over the years I have learned that when my daughter does not fully understand what she is being told, she will do what we all do, that is, guess, based on the context. Unfortunately, because of her disability she often guesses wrong.

Some of the problems confronting au'ism are no different from those of early intervention in general: a need for more and better research on program effectiveness so that decision making can be research based, for example. Another example is the overriding importance of family support. What does seem to separate autism from other developmental disabilities is the regularity of seductive 'cures' that keep emerging: from megavitamin therapy to strict behavior modification. Often they arise outside the traditions of education or early intervention and frequently they overlook the fundamental needs of the children as children.

Staff development, training of all staff working with the autistic child, was another need that was strongly expressed by conference participants. Professional providers as well as parents need information and training.

One speaker emphasized the importance of a developmental approach to working with children with autism. The speaker suggested periodically posing the following questions: What do most children at this developmental stage do? What do any children need at this age? This approach can be especially difficult for parents, particularly those whose autistic child is the first-born. These parents may have little or no experience to draw upon. (As a parent, I had this difficulty myself.)

Similarly, in choosing an intervention approach, parents and providers should be careful not to make compliance with adults a goal in itself. Past uses of behavior modification techniques often made this mistake. Such an approach can be self defeating. The child's behavior may become more socially acceptable, but this result occurs at the expense of autonomy and self reliance, characteristics that become more and more important as the child grows.

In a discussion about the so-called Lovaas method, one participant made the following point: 'Look at Lovaas' contributions to autism. He has shown that kids with autism can learn and that early intervention and intensity of service are important; further, he has gotten the attention of policy makers.'

As indicated above, one of the most critical needs emerging from the conference is the need for research, especially around outcomes and efficacy. Following are some of the key questions that were posed for researchers:

- **Is there a correlation between family support and positive outcomes?**
- **What are the long-term outcomes of discrete trial intervention (E.g., role, speech, aggression, learning)?**
- **How will outcomes be different with different interventions?**

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Questions about research frequently accompanied questions about costs. One speaker made the important point that programs for children with autism are expensive, no matter which method or combination of methods is chosen. The additional point should be made, however, that this early expense almost certainly will save money down the road, as the autistic child enters elementary school. Effective early intervention is likely to prevent the need for expensive separate programs, for example. Here, too, more research is needed, especially long-term research.

The following questions that were posed by conference participants are of special importance to parents and others serving on Interagency Coordinating Councils:

- **How do we establish operational models in our communities, not just theoretical models or models that exist only in other communities?**
- **How do states take all the information and integrate it into effective programming, without prescribing one model or approach for the whole state?**
- **How do states develop a set of individualized interventions without developing a "state system"?**
- **How can we establish methods for disseminating information to parents and professionals and for providing training and technical assistance?**

As a parent myself, of an adult daughter with autism, I recognize the dangers of parents becoming teachers. While we certainly want to instill in all our children certain standards of behavior, we must be cautious about constantly teaching, especially correcting, our children with autism. When we fall into that trap we undermine the healthy growth of self esteem in our children. While such a caution applies to all our children, it is especially important for our autistic children because it is so tempting to continually correct them: their language, their social behavior, their obsessions. One of the speakers made this point succinctly by urging that we see the "child" first, then the autism.

Currently, there is a rich supply of helpful literature on the subject of autism. Two recently published books are especially useful to parents and anyone working with children with autism:

Thinking in Pictures and other reports from my life with autism, by Temple Grandin. Published in 1995 by Doubleday, this book is widely available. In just 206 pages, Temple Grandin explains what it has been like to grow up autistic. She summarizes the latest findings about autism and vividly describes her own experience. In addition to her career in designing pens for livestock (she has a Ph. D. in animal science from the University of Illinois), Grandin has become a national expert in autism. She has talked with hundreds of parents and people with autism.

Out of Silence, by Russell Martin, was published by Henry Holt and Company in 1994. Martin writes about his nephew Ian, a boy with autism, growing up in Colorado. Always keeping his nephew as the central focus, Martin examines the latest chemical and neurological research on autism and the latest findings and theories about language development.

Many more excellent books and articles about autism are now available. NEC*TAS is in the process of compiling a bibliography on this topic. Temple Grandin lists several resources at the end of her book. Parents, educators, therapists, and administrators can benefit from Grandin's closing comments:

I would like to conclude...with a warning. There is no magic cure for autism, and parents must be cautious to avoid being misled by extravagant claims made by people who are promoting their brand of therapy. Treatments that are effective should work with reasonable amounts of effort. A treatment program that works for one child may be useless for another. Treatments and educational programs that are effective can be implemented without spending huge sums of money. Dedicated parents and good teachers have made their own effective programs after reading different books. They did not have to have expensive training. A parent should follow his or her own good instincts. Try different programs or methods and keep the things that work and eliminate the things that do not work. Combining several different approaches is often effective. (Grandin, page 222).

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